

IMMUNIZATION REGISTRY FOCUS GROUP STUDY

September 15, 1998

African American , Lower Education

Baltimore, MD

Moderator: Barbara K. Hairston

SECTION I: GENERAL IMMUNIZATIONS AND HEALTH CARE

This group included 8 respondents, 2 male and 6 female. Almost all were doing something to take care of themselves ranging from the spiritual to the physical, including such activities as taking vitamins, getting regular check-ups, and limiting the amount of junk food in the diet.

I. Prevention

Respondents mentioned the following childhood and chronic diseases which concern them.

- Sick cell
- Hepatitis
- Cancer
- AIDS
- Pneumonia
- Lead poisoning
- Chicken pox
- Measles
- Mumps
- Whooping cough
- Bronchitis

II. Immunization

This group was pro-immunization. Quite a few kept their own immunization records and schedules.

A. *Reasons not to get vaccinated*

Though the respondents were not in agreement, they were able to identify a list of reasons that others do not immunize their children.

- Lazy
- Lack of knowledge
- Rejection of the concept of immunization, i.e., fighting the disease with the disease
- Fear or rejection of the contents of the vaccine.
- Religious reasons

Some people are like, I'm not giving my child that, it was tested on animals, or maybe it's what in. If pork is in it in any kind of way and you have a Muslim person and they're true to their faith, they're not going to get that shot.

B. *Reasons to get vaccinated*

The following comments illustrate respondents' attitudes towards immunization. Generally, the benefit of minimizing the risk of disease, being a good parent, school entry requirements, and adhering to the law were the most common reasons.

To help your child with those diseases.

So they won't get sick.

The parent feels more comfortable, knowing that diseases are spread in the school environment.

I mean you tell your kids, you get what you need not what you want, so to me immunizations are something that they need, that they should have and not whether I want them to have it or not.

It's a law thing to me.

You have to have that, like their shots up to date for them to get in school.

C. *Ways parents are reminded of vaccine schedule*

Some parents were more organized than others or placed more importance on good record keeping. Some kept track of their immunization requirements with their own documentation. Others relied on the doctor to call and remind them. That reminder might take the form a phone call or a post card.

I carry my children's shot record books around with me. They're in my pocketbook now cause to me I never know, I may have to go somewhere and to me it's like identification.

So they tell you to call back. If you don't call back, at some point in time they're going to mail you something to remind you, a reminder.

I get a card mailed to me from the doctor.

D. *Methods of tracking*

Respondents did not think of this aspect of record keeping as a big deal. Some kept their own records, but most relied on the their doctor or the school to notify them that immunizations were due. Respondents cited the following ways of tracking their children's immunization schedules:

Immunization cards.

If you are taking your kid for regular checkups, they mail you a postcard so that you know that it's time to make that appointment or they make the appointment for you.

The [school] will let you know if they don't have a record of your child being up to date. They look at the sheet and say hmm, they missed a shot. They can call you and tell you that child missed a shot.

SECTION 2: IMMUNIZATION REGISTRIES

I. Initial reactions to the idea of a registry

There was no unaided awareness of immunization registries. The description of the registry generated a favorable reaction. It was viewed as a back up for parents who might forget, or if responding to an emergency failed to carry it with them.

- Areas of concern:
 - A misinterpretation of “area where you live” led to the perception that the availability of the information would be narrow in scope.
 - How the information is transferred. This concern was actually a way of surfacing more fundamental concerns with the registry. These included issues of confidentiality, access, and potential for fraud.
- Accessibility of information was a perceived advantage of the registry. Knowing that other parents would not be left to their own devices with respect to immunization also seemed to be an advantage.

II. Content of the registries

A. Initial reactions to the type of information typically in a registry

- Respondents, particularly father's and guardians, expressed concern over the requirement for the mother's name. Respondents seemed to assume that the mother's name indicated that she was the responsible party for that child, to the exclusion of the father. There was no interpretation that the name could simply be an identifier.
- The lot number raised questions which the group was able to answer immediately. It was agreed that the lot number was primarily for tracking if something went wrong.

Some kids have gotten the disease after they've given them, especially polio.

Like recall.

The need for the child's gender was questioned. As respondents themselves tried to make sense of the need for this information they tied it to gender specific conditions/diseases.

Well maybe some things that affect women that don't affect men you know. Men don't have to take hormone pills.

B. Reactions to including home address and phone numbers

- Including the name and address focused respondents' attention on issues related to security. The security issue was related as much to the adults in the family as the children. The possibility of stalkers or child predators gaining access to this information was a concern.

Too much information.

Because somebody may be up in there trying to stalk me.

They stress that with my child in school because they get on computers and they can't put any type of information, their whole name they can't even put in there, so that's why I'm kind of hard on that, because we have some perverts.

C. Reactions to including parent or child social security number

- The possibility of including the social security number came up on an unaided basis.

You're missing one important thing, in this day and age you need a Social Security number. You need a notification number.

If you call and say I want to make an appointment for my child and they might say give me a name and they're not spelling your name right, they'll ask you for the Social Security number and they punch it in and the child's name come up.

- When the idea of including a social security number was introduced, the group had a mixed reaction. Again, security and the consequences of having the information leak were a concern. Respondents described scenarios where a social security number in the wrong hands could ruin a person's life.

For one thing, especially if everyone's real concerned about confidentiality, if someone gets a hold of your Social Security number, they can ruin your life. I mean they can track you through life.

My daughter used her son's Social Security number for gas and electric purposes, whatever she felt she needed to use it for. I didn't know it at first but when I found out I went down to the gas and electric company and told them about this and had them take it off his record because she was ruining his credit.

- Others recognized that social security numbers are already being used to ensure unique identification.

My daughter's medical number is her Social Security number.

D. Reactions to including health care members enrollment (WIC, Medicare numbers)

The key issue with the use of these numbers is that they single people out. Respondents quickly noted that not everyone receives WIC or Medicaid benefits, nor do they receive those benefits for life. The usefulness of this information was questioned.

Everybody doesn't get WIC.

It only lasts for a certain length of time, what [age] 5?

What you going to do for the ones that's not getting it?

III. Access

The interpretation of the term access influenced how respondents felt about who should have access. There was one interpretation which suggested that access meant actually being able to get into the database. Others interpreted access as being able to request the information.

I'm hearing who can go in there and change data or go in there ...

I should be able to go get it, not like going and changing things.

A. Who should have access

Generally, respondents agreed that this should be a short list, though they did not completely agree on who should be on that list.

- You [parent] and your doctor.
- Schools, school nurse
- Parents

B. Who should not have access

Respondents wanted to limit access to those who needed to know about the child and the child's immunization record. They tended to reject bigger picture public health users.

- General researcher
- Government

C. Reactions to ideas of linking registry by computer to other health information systems

- Respondents saw both positives and negatives related to linking. One concern with linking was the idea that if different health systems were linked, the systems actually became one system, which raised the issue of access.

It sounds like just one whole system. Each separate compartment can go to one main computer and just access what they need.

- Respondents recognized benefits that could be gained with linking information, but questioned whether it would offset by the disadvantages. The key disadvantage for some was the potential for fraud. Assuming no fraud, the following benefits were identified:

It's quicker because the information is right there and you don't have to get it word of mouth from their parent or whoever is registering that child or at the health facility, they may need to know some information because maybe for some reason or another the child can't drink milk.

I think it will be less headache, less running around and if you need something right then, that day, you can get it.

It saves you a lot of time.

IV. Consent and inclusion

A. Reactions to “opting out”

Most of the respondents had issues with “Opting Out” because it did not appear to give parents a choice. Respondents attributed this to the possibility that parents might never see the notification about the registry. Assuming mail service, respondents believed that they might not receive notification, or, that they might treat it as junk mail.

It's not good because people move all the time. Some people may just not get the notice in time

You might be supposed to take care of it now, you don't get the letter until 3-4 days later, I mean that's not your fault.

- Advantages

Saves you the trouble. It's to the advantage of those who know they want to be on a registry, it's to that person's advantage because they don't have to do anything and they're in there.

- Disadvantage is being penalized for not reading the mail

- Opting out was perceived to be a helpful alternative for the public at large because it would take the responsibility for registration from parents who would not take care of registration.

B. Reactions to “consent” option

- The initial reaction to this option was favorable. This was clearly the option which allowed the respondents to feel they had control over their own information and their families. More of the respondents selected this option as their preference.

I gave you permission. It's like you felt you had a part of it. When you sign a consent they're saying OK, you're listening to me. I'm your boss now so if you don't sign it and they going to do it.

Makes you feel important.

I agree with it you know because --- you happen to know you taking some type of initiative to be part of it.

- The overall idea of the registry was believed to be a good one. A concern that surfaced related to the consent option is that if people do not do anything, it jeopardizes the registry.

It's not going to be a registry if it [isn't] being done.

- Respondents did not give other people credit for doing what they considered the right thing.

You're not really looking out for the masses. The majority of people just won't send it back.

But looking out for yourself, I would go with consent also, but what we have to do as a people is look out for the other guy, looking out for the other guy and saying no choice.

Most people just aren't doing what they supposed to do and that's like messing their child up. Some people need someone to do stuff for them. That's, nobody's doing anything for you, you have to do it for yourself.

If I was to be selfish, that's the category I would choose, consent, because I know I would send it back but to think of the general public, I would say that's not a good one because I don't think those that need to respond would respond.

C. Reactions to “automatic” option

- Respondents found this the least favorable option, initially. The issue seemed to be more of robbing respondents of an element of control of their lives. In order for this option to be palatable, respondents suggested that at a minimum it should inform if there is no consent.

It's not good. That's just having a person make a decision for you. You should have your own choice.

- From a public health perspective this option was much more favorably received. It seemed that this group, a lower education group, did not feel that those with whom they came in immediate contact could be relied upon to do the right thing. Automatic seemed to be more palatable by taking it out of the context of consent and putting it into a context of assuming responsibility.

I have to be unselfish on this because it's more of you all than it is me. I'm telling you I want to know if you took a bath today, I want to know that people and kids my kids are going to be around are getting their shots and I know if there's no choice then it has to be done.

I would feel more comfortable with no choice because if they don't have a choice it could be kept up with better.

SECTION 3: ATTITUDES AND PERCEPTIONS OF REGISTRIES

I. Most important benefits of registries

- Serve as a vehicle with which to make more people get immunized.

That it takes place, that's more important than the records or whatever if it takes place.

Updated.

- Having the information readily available when needed.
- Minimizes the chances of a mistake in the immunization process.

If they have access to the medical records, they won't get shot with the wrong medicine he might be allergic to.

II. Greatest concern(s)/biggest risk (s)

Generally, respondents were most concerned about security, access, confidentiality and the possibility of fraud. Human nature and curiosity together explained one respondent's concern.

Someone could just sit here and they just start discussing her child. Well okay, I don't think she had this. Well let's go punch it up. I mean they can just do it for any reason.

III. Influence of health care provider in decision to participate in a registry

Though the group generally wanted to communicate an image of being in control and empowered, almost all agreed that the doctor could influence their decision to participate.

IV. Suggestions/comments to people who are responsible for how system works

We think it will have its advantages and disadvantages but it's a good idea.